



MAKING THE FINAL DECISIONS (SUMMARY):

**A report on the factors contributing to a positive
experience of advance care planning for people
with intellectual disabilities and life limiting
conditions**

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"Not everything that is faced can be changed, but nothing can be changed until it is faced."

- James Baldwin

Making the Final Decisions: A report on the factors contributing to a positive experience of advance care planning for people with intellectual disabilities and life limiting conditions

This report is a summary of a research project that has recently been completed. A full report and an easy read version are available from the Donald Beasley Institute, www.donaldbeasley.org.nz¹.

This research was prompted by a need to find out what makes advance care planning successful from the perspective of people who have intellectual disabilities and life limiting conditions. Few people with intellectual disabilities have had an opportunity to develop their own Advance Care Plan (ACP), meaning that they are very much at risk of not having their wishes met at the end of their lives (Bigby, 2004). Although there is good information about carrying out this type of planning with the general population, there is very little that relates to people with intellectual disabilities. More information was needed to ensure that people with intellectual disability can receive good information, be less afraid, and be in control of how they are supported at the end of their lives.

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1.0 What is Advance Care Planning?

Advance care planning means making plans for the end of life. It can be done pro-actively (when people are well), or by people who are unwell or dying. It usually includes talking and making choices about:

- Where the person wants to die
- Things the person wants to do
- How the person wants to be cared for
- Legal and financial decisions
- What the person wants to happen after they die

The benefits of advance care planning include:

- Providing a chance to understand what the future might hold
- Allowing people to identify what treatments/procedures they would and would not want
- Helping people, their families and healthcare teams to plan for the future
- Making sure that others know what the person would want if they became unable to speak for themselves (NZ Advance care planning Co-operative, 2015).

“Talking about death doesn't bring death closer. It's about planning for life. Without communication and understanding, death and terminal illness can be a lonely and stressful experience, both for the person who is dying and for their friends and family.” Dying Matters, <http://www.dyingmatters.org/overview/why-talk-about-it>

¹ Reports can be found on the Donald Beasley Institute website – they can be found in the Frozen Funds section of the Publications page.

2.0 Research Process

The research took three years, which was longer than anticipated. The delays were largely due to difficulties in recruiting primary participants. The primary participants needed to have an intellectual disability and a life limiting condition, know that they were dying, be developing an advance care plan, and be able to take part in an interview. This was a difficult set of criteria to meet, but was important in ensuring that the focus was on the perspectives of people with disability.

Four primary participants were recruited to take part in the research. The four people (Frankie, Tony, Lee and Alex - not their real names), varied in age from 28-68 years old. Three were European, and one was Maori. They lived in different locations within New Zealand and were supported by two different residential service providers. They lived in a range of supported situations. Three had family/whanau take part in the research, and all had staff from their disability service involved, including Managers, Health Advisors and Support Workers.

Each primary participant was interviewed twice (other than one person who died prior to the second interview), as were their support teams and families. This allowed the researcher to follow progress and changes to the planning process over time. In addition, each person's service file was reviewed, to identify how the plan had been documented and how it had been shared. All information was analysed to identify the common and important themes.

3.0 Findings

The research found that many things affected how people with intellectual disability felt about advance care planning, including these key factors:

- Deciding when to start the ACP
- Their support team members' facilitation skills
- The support given to people's decision-making
- The content of the plan

Table One below lists the full set of factors that helped advance care planning to be successful for the primary participants. When these factors were omitted or applied negatively the primary participants were either less satisfied or had incomplete plans. For example:

- Tony was reluctant to take part in his advance care planning, so his support team and family did lots of things to make sure the process was as engaging as possible for him. They focused on planning his life, not just his death, so that he had plenty to look forward to and wasn't overwhelmed by thinking about dying. They made sure they still covered all of the information about end of life options. They did this gently and went at Tony's pace.
- Alex's support team had a lot of experience in supporting people who had died. They were comfortable talking about death and dying. They spoke openly with Alex, and involved her in all discussions and decisions. She made decisions about treatment options, funeral plans, her living situation, and who she would want to decide things for her if she couldn't do this herself.
- Frankie's support team were less comfortable talking about death and dying. They talked to Frankie about funerals, without Frankie knowing that was to help plan his own funeral. Most of the discussions with Frankie happened in a similar way – hypothetical rather than specific. It is unknown whether being more explicitly/directly involved would have altered his choices.
- In one person's case, a lack of clear information about who could make advance directives (such as a non-resuscitation order), and in what situations, lead to discussions about this being had without her.

- Lee’s family took some persuading to start the advance care planning process. In the end they were pleased with how it went, and said that starting as early as possible would have been better than waiting until they were ready.

Table One – Factors Influencing the Success of Advance Care Planning

Main Themes	Sub-Themes
Deciding when to start	Starting as soon as possible
	Starting when I am ready <ul style="list-style-type: none"> - Participant - Family - Staff
Support Team Member Facilitation Skills	Comfort talking about death and dying
	Being open and honest
	Introducing ACP gently
	Supporting Emotional Wellbeing
	Ongoing conversations
	Working as a team (collaborating)
	Sharing the plan
Supporting people’s decision making	Having clear information <ul style="list-style-type: none"> - Treatment options - Legal and Financial matters - Support/service information -
	Adapting the process to suit me <ul style="list-style-type: none"> - Going at my pace - Drawing on my past experiences - Making sure I understand
	Making my own choices
Content	Planning my life (not only my death)
	Covering typical content areas <ul style="list-style-type: none"> - Where I want to die - Treatment options - After I have died (my body) - My funeral - Advance directives - Legal and financial matters
	Having a resource to guide us

3.1 The Most Important Factors to People with Intellectual Disabilities

The primary participants were very clear that the MOST important things to them were:

- Planning my life (not only my death)
- Making my own decisions
- Going at my pace
- Being open and honest
- Making sure I understand

Primary participants said:

*"I tell people, I'm still here aren't I? I'm sick of talking about f***ing dying!" [Tony]*

"They could get more things for us to do here" [Frankie, speaking about what is important]

"I'd say 'keep on going, have a good life'" [Lee]

"I make the final decisions, 'cause I'm an adult, and I'm responsible" [Lee]

"I want to be cremated like my Mum and I want the staff to come to my funeral, and Dad to come up here." [Alex]

"Just be honest, ask questions and don't worry. Don't try to dodge things." [Lee]

Support team members and family/whanau agreed. They said:

"She wants them to be straight with her, because otherwise she keeps thinking about things all the time." [Family/whanau member]

"I absolutely love the fact that Lee is so involved in it when it's so important – it's all her wishes, her thoughts" [Support team member]

"He'll go back to the marae, yeah, we'll do that. That's no special thing, eh. It's just protocol in our life. It's really up to him, ain't it?" [Family/whanau member]

"I didn't know that she had thoughts like that, had even gone there [speaking about cremation vs burial], so, you don't know until you go and ask." [Support team member]

"And although it's hard knowing that a person might be at the stage it's also good not to put your head in the sand." [Support team member]

3.2 Facilitation and Collaboration

A key theme identified through the research was the importance of having someone to help pull the ACP together and make sure that the right people were actively involved. For each of the primary participants, a senior member of their disability service support team took on that role. Three of these were Health Advisors and one a senior Service Manager. They made sure that the primary participant, their family/whanau, other disability service team members and medical professionals were involved and worked together.

The support team members described advance care planning as being much like any other person-centred planning process - they worked as a team and adapted things to suit the individual. In this case they didn't have a lot of information to guide them, so they adapted what was recommended for the general population.

Support team members said these things:

"We have to do it in little bits and pieces. Tony understands but we can't have a whole conversation about it [in one go]. You can only go at the person's pace and with what they want to talk about. It's about giving the information but not needing them to bring it up." [Support team member]

"And explain it to her so she can understand. You can't sugar coat it." [Support team member]

*"He can't read or write, so we had to do visuals and we had to be **really really straight up** and not muck around, but be careful not to put words into his mouth."* [Support team member]

"We had a chat a while back about if he would like to stay at home, and he said no [abbreviated]. So, it's about making sure that the information is the right information, eh. Cause sometimes he thinks that something is going to happen, but when it does it's a little different." [Support team member]

"He's Maori, so again we are really wanting to support the whole whanau system." [Support team member]

The importance of facilitation skills has also been noted in research in the general population. For example, Bekkman et al (2014) found it to be very important to respect people's individuality and choice making by:

- Connecting with the person
- Helping the person understand new information
- Familiarising the person with transitions and changing needs
- Trying to understand their wishes and important decisions.

The research found that there was an area of skill outside of person-centred planning that the lead support team members also had. They all had a high level of comfort and experience in supporting people who were dying or who had died. One had a specific palliative care background. They all felt that they wouldn't have been able to take on the lead/facilitation role without that training and/or experience.

This research demonstrated the value of having an experienced disability service health advisor or senior staff person involved in advance care planning – they were an integral part of ensuring that the primary participants could understand what was happening and be fully involved. They directly contributed to the plans being very strong in the areas of a) where people wanted to die, b) things they wanted to do before they died (bucket list type activities, and life goals), and c) what they wanted to have happen after they died (funeral plans, distribution of belongings, how their body should be treated, cultural rituals). However, the plans were much weaker, and often had sections missing information, in regard to d) how people wanted to be cared for (treatment preferences) and, e) legal and financial matters (wills, advance directives). It is interesting to note that these last two topics are usually the focus in plans that are led/facilitated by health/palliative care professionals, as is the norm in the general population. Perhaps this shows a difference in the way that plans are facilitated by the two very different groups of professionals. It is possible that increased collaboration between disability and health/palliative care professionals would allow each service to make

the most of the other's skills. It could help to address the gaps/weaker areas that have been described above.

Support team members said these things:

"I think we just need to realise because we're not the health professionals, so we really [need to] get some knowledge and ideas from health advice, or the doctor and the people involved, like the hospice and the [specialist] clinic."

"For me, the one thing that's been really good for him, is to have lots of lots of avenues to go and have those conversations with."

"We're hoping that there's enough grey matter between us that we can cope."

"And um, I think it's quite good sometimes having different ideas, and I think that when it gets to that real time of different drugs and treatments and things like that then I would expect them to take the lead, and I can do the bit of giving information ...connecting the dots for him."

3.3 Starting Early

In this study the primary participants, as well as their disability service support teams and family/whanau, identified that it was best to start developing an ACP as early as possible. This is similar to research findings in the general population (Bernacki and Block, 2014). For example, Lee's family put off starting an advance care plan for several years. Once they started they found that it wasn't as upsetting or difficult as they thought it would be. It gave them some relief to know that the planning had been done.

Support team members thought that having an ACP resource/template was one of the things that helped them to get started. Three of the four people used Living Well (Helen Sanderson and Associates, 2000) as their ACP template. Living Well was specifically developed for people with intellectual disability, and met people's needs. Using Living Well helped support team members know what to say and how to start conversations, and made it easier to find out what the primary participants thought.

Support team members and family/whanau said these things about getting started:

"Yes, as hard as it might be, get the discussion going, get something simple put in place." [family/whanau member]

"[Living Well] helped me from putting words in her mouth." [Support team member]

"To be honest I don't think I would have thought about asking a person to decide about different aspects around death. It [Living Well] was fabulous." [Support team member]

"[Using] it [Living Well] brought up things that weren't even in the book. Just talking about it she was like "oh actually I don't want this at my funeral, and I do want this", and things that the book didn't specifically ask as well. It's just because we were having the conversation already." [Support team member]

"Know your document, and just let it unfold as it goes. So have your base questions, and then just let it flow from there." [Support team member]

3.4 Addressing Distress

Some support teams expected that the primary participant could become upset during advance care planning. These teams planned how to support the person if/when this happened. Planning this in advance helped the primary participants to feel safe and supported. However, not all of the support teams expected distress or planned for it. For example, Lee's team hadn't expected Lee to become upset because Lee initially seemed quite happy about developing an ACP. They discovered that a few days after each end of life conversation Lee's behaviour would become challenging.

The research showed the importance of planning in advance how to support people if/when they become distressed or upset.

The support team members also found that the end of life discussions took an emotional toll on themselves. In most instances they, and their managers, hadn't planned for how they would receive support and kept their distress to themselves. Again, this support should be pro-actively planned for.

Support team members said these things:

"He doesn't seem to get distressed about it now. I think he's getting used to the idea."

"But read your people, because um while Lee looks ok on the outside, once it sinks in, it can fall apart and you've got to be prepared for that. I wasn't. I wasn't. Because Lee is so vibrant so out there, , I came away thinking it was so good, yes, we'll come back to it in a couple of weeks....but a few days later, bingo, ouch....that was a learning curve...."

"It has been difficult. It's a very emotional thing to do. It's horrendously emotional. You have to make sure that you're in the right frame too. I know, leading up, that I've got that to do, and so I always try and get ready at home and prepare myself for that hard part of the day."

3.5 Inequitable Access to Advance Care Planning

Apart from Alex, Frankie, Lee and Tony, 11 other people were considered as possible primary participants. None of the 11 met the eligibility criteria because they had not been told that they were dying. In all instances the rationale given for the lack of disclosure was a concern that the person would not cope with knowing, or would not understand. This fits with what other research tells us - a) this is also common with older people in the general population, b) there is less openness to discussing death and dying with people who have intellectual disability, even right at the very end of their lives (Todd 2005; Tuffrey-Wijne et al, 2006), (Weise et al, 2013).

However, research tells us that most people prefer knowing what to expect at the end of life. Talking about end-of-life issues does not cause any more distress than not talking about it (Bernacki and Block, 2014). In actual fact, discussion about end of life care, and taking part in advance care planning, leads to these outcomes:

- Better quality of life
- Reduced use of non-beneficial medical care near death
- Care that matches people's goals
- Positive family outcomes
- Reduced costs.

We also know that not talking about end of life issues has some negative outcomes (Bernacki and Block, 2014). These include:

- Receiving treatment and care that don't match your goals

- Worse quality of life
- Prolonged death with increased suffering
- Worse bereavement outcomes for family members
- Increased costs without benefit to patients.

In this study, people with intellectual disability coped with the news of their diagnosis and prognosis. They were able to take part in a successful advance care planning process.

Withholding information to a person with intellectual disability who is sick and dying means they can't be involved in any meaningful planning for the end of their lives. It contradicts the rights in the United Nations Convention for the Rights of Persons with Disabilities.

4.0 Conclusions

The primary participants had strong ideas about how advance care planning helped them. They wanted to be involved in the critical decisions in their lives and provided rich information on ways to continue this support. They also challenged support teams and their families/whanau to keep a balanced perspective so that they keep on being supported to live, rather than just being supported while they die.

The support teams and families/whanau involved in this study demonstrated how to encourage a positive experience of advance care planning for the people they support. They shared their challenges in negotiating the complex situations for which they were often unprepared. They should be congratulated.

The purpose of this research was to hear from people with intellectual disability about their experiences of advance care planning. The research highlighted some possible insights into why so many potential research participants were excluded by noticing the hesitancy and concerns expressed by some support team members and families/whanau. A number of people with intellectual disability could not be part of this research because they did not know that they were dying. More importantly, they could not then be involved in planning about their end of life. This raises important challenges for health professionals, families, disability staff and agencies, in making real the rights of people to be involved in decision-making about their lives.

5.0 Future Research

More research about advance care planning and intellectual disability is needed. We need to understand better:

- How to make sure that people with intellectual disability are fully involved in making decisions about treatment preferences and advance directives
- Ways for medical/palliative care professionals and disability service providers to work together on advance care planning
- What needs to be done differently when advance care planning takes place pro-actively (when people are well)

6.0 Recommendations

We are still learning about the best ways to support people with intellectual disabilities with advance care planning. We hope that the way that it is approached and implemented will continue to evolve, grow and strengthen.

We hope that service providers and health professionals think about our recommendations. Doing things differently would improve access and support to advance care planning for people with intellectual disabilities.

- 1) Encourage health/palliative/ACP professionals to initiate and lead the advance care planning process for people with intellectual disabilities, with support from disability service providers
- 2) Encourage people with intellectual disabilities to be involved in advance care planning when they dying, but also when they are well
- 3) Disability service provider organisations to link with organisations in the health and palliative care sectors (such as the NZ ACP Cooperative, and Hospice NZ) to ensure that people with intellectual disability are represented and considered in policy, research, and processes related to advance care planning
- 4) Continue implementing policies and procedures within disability services to ensure that people with intellectual disability have positive experiences and successful outcomes as a result of advance care planning

7.0 Correspondence

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